# DEPARTMENT OF HEALTH AND HUMAN SERVICES NATIONAL INSTITUTES OF HEALTH NATIONAL LIBRARY OF MEDICINE MINUTES OF THE BOARD OF REGENTS MEETING (VIRTUAL MEETING) September 14, 2021

The 188th meeting of the Board of Regents (BOR) was convened remotely on September 14, 2021, at 10 a.m. The meeting was open to the public from 10 a.m. to 3:30 p.m., followed by a closed session lasting until 4:15 p.m. The meeting adjourned at 4:15 p.m.

# **MEMBERS PRESENT** (Appendix A)

- Dr. Lourdes Baezconde-Garbanati, University of Southern California
- Dr. Suzanne Bakken, Columbia University
- Dr. Kristi Holmes, Northwestern University
- Dr. S. Claiborne Johnston, The University of Texas at Austin
- Ms. Jennie Lucca, The NIH Children's Inn
- Mr. Neil Rambo, NYU School of Medicine, Chair (retired)
- Dr. Heidi Rehm, Massachusetts General Hospital
- Dr. Nancy Smider, Epic Systems Corporation

#### EX OFFICIO AND ALTERNATE MEMBERS PRESENT

- Dr. Teeb Al-Samarrai, Office of the Surgeon General, U.S. Public Health Service
- Col. Thomas Cantilina, United States Air Force
- Dr. Joseph Francis, Veterans Health Administration
- Dr. Lauren Maggio, Uniformed Services University of the Health Sciences
- Dr. Brent Miller, National Science Foundation
- Dr. Hassan Tetteh, United States Navy
- Mr. Paul Wester, National Agricultural Library, U.S. Department of Agriculture

#### EX OFFICIO MEMBERS NOT PRESENT

- Col. Kent DeZee, United States Army
- Dr. Mary Mazanec, Library of Congress

#### **CONSULTANTS**

- Ms. Jane Blumenthal, University of Michigan (retired)
- Dr. James Cimino, University of Alabama at Birmingham
- Dr. Omolola Ogunyemi, Charles R. Drew University of Medicine and Science

#### SPEAKERS AND INVITED GUESTS

- Dr. Jessica Ancker, Vanderbilt University
- Dr. James Anderson, Division of Program Coordination, Planning and Strategic Initiatives, NIH

#### MEMBERS OF THE PUBLIC PRESENT

- Dr. E. Andrew Balas, Augusta University/Friends of the NLM
- Dr. Clarion Johnson, Yale University/Friends of the NLM

Ms. Loretta Jurnak, Technical Resources International, Inc.

Ms. Joyce Wanga, Technical Resources International, Inc.

#### FEDERAL EMPLOYEES/CONTRACTORS PRESENT

Dr. Patricia Flatley Brennan, Director, NLM

Mr. Jerry Sheehan, Deputy Director, NLM (on detail)

Ms. Anne Altemus, Office of Communications and Public Liaison, NLM

Ms. Dianne Babski, Division of Library Operations, NLM

Dr. Dennis Benson, National Center for Biotechnology Information, NLM

Dr. Olivier Bodenreider, Lister Hill National Center for Biomedical Communications, NLM

Dr. James Rodney Brister, National Center for Biotechnology Information, NLM

Ms. Marie Collins, Division of Library Operations, NLM

Mr. Todd Danielson, Office of the Director, NLM

Mr. Ivor D'Souza, Office of Computer and Communications Systems, NLM

Ms. Jennifer Diffin, Division of Library Operations, NLM

Ms. Mitzi Diley, Office of the Director, NLM

Ms. Jolie Dobre, National Center for Biotechnology Information, NLM

Dr. Anna Fine, National Center for Biotechnology Information, NLM

Dr. Valerie Florance, Office of the Director, NLM

Ms. Jessica Freim, Division of Library Operations, NLM

Ms. Kathryn Funk, National Center for Biotechnology Information, NLM

Dr. Elisa Golfinopoulos, National Center for Biotechnology Information, NLM

Dr. David Higgins, Office of the Director, NIH

Dr. Zoe Huang, Division of Extramural Programs, NLM

Dr. Michael Huerta, Office of Strategic Initiatives, NLM

Ms. Christine Ireland, Division of Extramural Programs, NLM

Dr. Kenneth Koyle, Division of Library Operations, NLM

Ms. Michelle Krever, Division of Extramural Programs, NLM

Mr. Luke Kudryashov, Associate Fellow, NLM

Dr. David Landsman, National Center for Biotechnology Information, NLM

Ms. Wei Ma, Office of Computer and Communications Systems, NLM

Ms. Jennifer Marill, Division of Library Operations, NLM

Dr. James Mork, Lister Hill National Center for Biomedical Communications, NLM

Ms. Stephanie Morrison, Division of Library Operations, NLM

Dr. Clem McDonald, Office of the Director, NLM

Ms. Margaret McGhee, Division of Library Operations, NLM

Mr. Patrick McLaughlin, Division of Library Operations, NLM

Dr. Virginia Meyer, Office of the Director, NLM

Mr. Thomas Murphy, National Center for Biotechnology Information, NLM

Dr. Ilene Mizrachi, National Center for Biotechnology Information, NLM

Ms. Jody Nurik, Office of Communication and Public Liaison, NLM

Dr. Kim Pruitt, National Center for Biotechnology Information, NLM

Ms. Queenmoore Okeke, Office of the Director, NLM

Ms. Deborah Ozga, Division of Library Operations, NLM

Dr. Richard Palmer, Division of Extramural Programs, NLM

Dr. Jeffrey Reznick, Division of Library Operations, NLM

- Dr. Christina Robinson, Lister Hill National Center for Biomedical Communications, NLM
- Ms. Leigh Samsel, Office of Strategic Initiatives, NLM
- Ms. Mary Sanders, National Center for Biotechnology Information, NLM
- Dr. Valerie Schneider, National Center for Biotechnology Information, NLM
- Dr. Stephen Sherry, National Center for Biotechnology Information, NLM
- Ms. Simone Stone, Associate Fellow, NLM
- Dr. Meryl Sufian, Division of Extramural Programs, NLM
- Ms. Samantha Tempchin, Division of Extramural Programs, NLM
- Ms. Kimberly Thomas, Office of Strategic Initiatives, NLM
- Dr. Tony Tse, National Center for Biotechnology Information, NLM
- Dr. Alan VanBiervliet, Division of Extramural Programs, NLM
- Mr. Frank Vitale, Associate Fellow, NLM
- Ms. Sam Kennefick Wilairat, Associate Fellow, NLM
- Dr. Rebecca Williams, National Center for Biotechnology Information, NLM
- Dr. Jane Ye, Division of Extramural Programs, NLM
- Dr. Teresa Zayas Cabán, Office of the Director, NLM

#### I. CALL TO ORDER AND INTRODUCTORY REMARKS

Mr. Neil Rambo, Chair, BOR

Mr. Rambo called the meeting to order, welcoming attendees to the meeting. Mr. Rambo welcomed two new board members (attending as consultants until their appointments are completed):

- Dr. James Cimino, MD, Director of the Informatics Institute, University of Alabama at Birmingham School of Medicine, Birmingham, Alabama
- Dr. Omolola Ogunyemi, PhD, Director for the Center for Biomedical Informatics, Charles R. Drew University of Medicine and Science, Los Angeles, California

Mr. Rambo also introduced Dr. Lauren Maggio, PhD, Associate Director of Scholarly Communication, at the Center for Health Professions Educations at the Uniformed Services University of the Health Sciences (USUHS), replacing Dr. Dale Smith as the *ex-officio* USUHS representative.

The meeting was broadcast to the public via streaming video at https://videocast.nih.gov/watch=43740.

#### II. REPORT FROM THE OFFICE OF THE SURGEON GENERAL

Dr. Teeb Al-Samarrai, MD, Director of Science and Policy, Office of the Surgeon General U.S. Public Health Service

Dr. Al-Samarrai provided updates regarding the Office of the Surgeon General's (OSG) efforts to address the ongoing coronavirus pandemic. With a primary focus of helping the nation get through the pandemic, the office has been working on increasing vaccine confidence and ensuring school safety through the emergence of delta variant with media appearances, White House press briefings, and listening sessions throughout the country. The COVID-19 Community Corps, established to increase vaccine confidence with assistance from trusted leaders within

communities, has reached 14,000 members. OSG has collaborated with this program by participating in regular events focused on reducing vaccine hesitancy and promoting conversations around booster shots and CDC guidance.

In July 2021, OSG released a public health advisory identifying health misinformation as an urgent health threat, highlighting the need to combat it with a collaborative societal approach. Specific organizations, such as social media and educational institutions, were identified as potential allies in combating vaccine misinformation and helping to vaccinate their communities. OSG acknowledged NLM as a critical partner in this effort and requested additional input on strategies to address the spread of health misinformation.

OSG is also focused on helping the nation heal after the pandemic, engaging with stakeholders to elucidate underlying issues and explore new ways to respond. The Surgeon General (SG) serves as the co-chair of an action collaborative working to address clinician well-being and resiliency, as well as burnout of frontline health care workers. A national dialogue on post-COVID life, approaches to future pandemics, and ways to increase justice and equity as a society is also necessary.

BOR members discussed OSG's activities focused on rural areas as well as minority groups and children. The SG has engaged with governors from states possessing rural areas. The SG is also working with the Department of Education on efforts to increase the safety of students as they return to school and to ensure these efforts reach students more equitably. Dr. Al-Samarrai will follow up internally to provide additional information on these topics.

#### III. MAY 2021 MINUTES AND FUTURE MEETINGS

Mr. Neil Rambo, Chair, BOR

Mr. Rambo noted the proposed dates for future BOR meetings, including the addition of the fall 2023 meeting date of September 12-13, 2023. There were no objections or conflicts noted.

**Motion:** The BOR approved the motion to accept the fall BOR meeting date of September 12-13, 2023.

**Motion:** The BOR approved the motion to accept the minutes from the May 11, 2021 meeting.

## IV. REPORT FROM THE NLM DIRECTOR

Dr. Patricia Flatley Brennan, Director, NLM

Dr. Brennan provided an overview of NLM's strategic plan, budget, and personnel updates, and the Advanced Research Projects Agency for Health (ARPA-H). She updated members on NLM's response to the COVID-19 pandemic, including the continued development of Phase 2 for the NLM video series supporting the NIH Community Engagement Alliance, computational assessment of antibody escape, and advancements in COVID-genome sequence data. NLM's Office of Communications and Computer Services have extended their support to the Value Set Authority COVID-19 initiative, helping hospitals and other funders to assess computational codes that describe value sets relevant to the clinical care of patients with COVID. NLM

continues to support the Accelerating COVID-19 Therapeutic Interventions and Vaccines (ACTIV) initiative to develop COVID-19 vaccine and therapeutic targets.

Dr. Brennan gave an update on NLM's efforts across the United States; 43 new awards have been processed for efforts to reduce community disparities, especially those resulting from the COVID-19 pandemic. Dr. Brennan noted improvements to NLM's operations, including an increase of automated approaches to MEDLINE indexing by 36.6% since 2020. The NLM Evaluation Coordinating Committee initiated an assessment of the Data Sciences program and NIH Preprint Pilot program. NLM has also leveraged Amazon Web Services' Open Data Sponsorship Program to make data repositories available to the public and transitioned the Library Services platform to the cloud.

NLM's building renovations are progressing and demolition work is almost complete. All History of Medicine objects and resources were safely moved for storage in an appropriate location, the data center upgrade processing includes plan to update the Plaza inside the building, and the building 38a space was upgraded with a temporary Board Room available for use by staff.

Dr. Brennan updated the BOR on the NLM budget by Fiscal Year (FY). In 2020, there was a total of an 8% increase due additions to the base budget and in support of work completed on behalf of NIH, the Centers for Medicare & Medicaid Services, and other federal agencies. Dr. Brennan noted a 10-million-dollar budget increase in 2020, awarded to NLM for their COVID-19 pandemic response. The Senate mark for the NLM's FY 2022 budget will be approximately \$475 million, but that the House of Representatives will approve a budget of \$487 million. Dr. Brennan also noted NLM personnel changes and welcomed those that recently joined.

Dr. Brennan introduced ARPA-H, a project with a mission of benefiting the health of all Americans by catalyzing health research breakthroughs; Dr. Brennan noted that the approval and implementation process for ARPA-H remains under discussion. ARPA-H is proposed to be housed at NIH but will remain separate from specific institutions within NIH. The purpose of this program is to leverage the collective knowledge, understanding, and expertise of the NIH while maintaining the unique culture as the NIH continues operations and research progress. NIH and the Office of Science and Technology Policy (OSTP) have conducted 15 listening sessions, engaging over 5,100 participants from nearly 250 organizations. The outcomes from the listening sessions included questions regarding the scientific portfolio and process elements of ARPA-H.

Dr. Teresa Zayas Cabán provided legislative updates focused on FY 2022 appropriations. On Friday, September 10, 2021, the House Energy and Commerce Committee released their draft legislation, that includes sections addressing public health concerns and proposes appropriations and authorizations for ARPA-H. It also mentions funds for pandemic preparedness response activities initiated by the CDC. Policy updates including Scientific Integrity activities at OSTP and the National Artificial Intelligence (AI) Research Resource Request for Information (RFI) were discussed. Dr. Zayas Cabán noted a recent White House memo listing research and development priorities, including COVID-19 pandemic readiness, climate change, and AI technology advancements.

#### V. WORKING GROUP BREAKOUTS

BOR members divided into four breakout groups. Group representatives summarized their discussions later in the meeting.

#### VI. WORKING GROUP REPORTS AND DISCUSSION

### **Strategic Planning**

Ms. Jane Blumenthal reported for the Strategic Planning Working Group. The Working Group discussed efforts of the NLM to gather evidence in support of the Strategic Plan and to comply with federal mandates on information gathering and reporting. The group discussed the use of the NIH Preprint Pilot program, the details of which have been presented previously. The group also focused on internal data gathering at the NLM, an ongoing and increasing effort to optimize resource use, reinforce alignment with the Strategic Plan, and report on evidence-building activity per the Evidence Act.

Working Group members discussed ways to encourage buy-in to internal data gathering efforts, emphasizing benefits including a more unified NLM, the use of common information systems across divisions, and reciprocal benefits to individuals and divisions within the NLM. BOR members discussed the National COVID Cohort Collaborative (N3C), with whom the NLM is working closely. The NLM is concerned about data linkages and the N3C has assumed a leadership role in evaluating privacy-preserving records linkages (PPRL) as a helpful tool in ensuring that all individual data is linked together.

#### **Research Frontiers**

Dr. S. Claiborne Johnston reported for the Research Frontiers Working Group. The Working Group discussed challenges in achieving diversity and gender inclusion, reviewing current diversity statistics in training programs. Proposals to address these challenges were presented and discussed. The group discussed improving communications regarding diversity and inclusion, stressing the importance of both in yielding the most effective solutions for the public. The need for deeper and continuing education of both leadership and trainees was also noted.

Additionally, the Working Group discussed strategies to increase diversity and inclusion: focusing on health equity to draw interest from minority candidates, strengthening candidate pipelines by piggybacking on other stakeholders, and fostering accountability in training programs. Dr. Brent Miller offered to put NLM members in contact with the National Science Foundation (NSF) for further information on their work to foster diversity and inclusion. The group also discussed partnership with professional organizations and the potential for collaboration and cobranding with the NLM.

#### **Collections**

Ms. Dianne Babski reported for the Collections Working Group. There were three presentations

by NLM staff to the Working Group regarding NLM data collection. First, updates on the MEDLINE 2022 Initiative were provided, focused on an automated approach to MEDLINE citations. With the acceleration Medical Heading (MeSH) indexing to be completed within 24 hours of new citation upload to PubMed, subject matter experts (SMEs) will be able to shift focus to the implementation of new indexing efforts. The group discussed ongoing work across NLM divisions to apply curation to chemical and gene information, consolidate indexing and maintenance, and automate data review.

Second, Working Group members were informed regarding terminology products and services managed by the NLM and were updated on their various implementations. NLM staff are currently drafting a vision statement encompassing goals for health data standards at NLM and how to achieve them. Third, the group was provided updates on the NIH Comparative Genomics Resource (CGR), formerly the Research Organism Data Resource (RODR), a cloud-based genomic data resource for reliable analysis of eukaryotic research organisms. Recent updates discussed included developments in administration and governance, refinements of the CGR Strategic Road Map and Release Plan, and the completion of user research to inform product release requirements. In addition to these presentations, the Working Group also discussed the upcoming effort to review and update NLM Collection Development Guidelines with particular focus on the CGR.

BOR members discussed the significance of the NLM Collections Policy to the collection and curation of data in partnership with numerous collaborators. Dr. Brennan noted the importance of protecting the rights of submitters and the authority of journals across the various pathways by which information is deposited into the NLM. BOR members discussed the application of the Federal Records Act to the storage of submitter-owned data by the NLM. The importance of modern data collection and storage practices, as well as the value of sequence data to society, were noted. BOR members further discussed conditions for full removal of human data from the NLM, noting that collections policies must evolve along with the proliferation of new technologies. The NLM currently relies on investigators and professional societies for input on evolving collections practices; their development will continue to be an ongoing process. BOR members plan to revisit this theme in future discussions.

#### **Public Service**

Dr. Lourdes Baezconde-Garbanati reported for the Public Service Working Group. The Working Group welcomed new BOR members to the ClinicalTrials.gov Modernization Working Group, also noting that all BOR members of the Modernization Group have committed to the effort through September 2022. The Public Service Group produced a report on the progress of the modernization effort, which will be shared with NIH leadership and posted to the BOR website; the group also discussed drafting a manuscript for publication to further disseminate information in the report. Group members noted the importance of the NLM's role as a central "data aggregator," serving primary stakeholders while also working to meet user needs and manage expectations.

The upcoming Beta launch of the new ClinicalTrials.gov website in Fall 2021 was noted, which will be available along with the current site. The Working Group discussed the importance of

collecting both qualitative and quantitative metrics for evaluation of the modernization effort, along with examples of both passive and active evaluation. Dr. Baezconde-Garbanati noted ongoing discussions on metrics and Beta releases, stakeholder and user engagement, automation support, data standards, the use of mobile devices, and cloud security. Dr. Brennan noted that ClinicalTrials.gov, as a resource maintained by the NLM in partnership with the NIH, represents a model for future capital investment in Information Technology (IT) at NIH.

#### VII. NIH STRATEGIC PLAN UPDATE

Dr. James M. Anderson, MD, PhD, Deputy Director for Program Coordination, Planning, and Strategic Initiatives, and Director, Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) in the Office of the Director, NIH

Dr. Anderson presented updates regarding the NIH-wide Strategic Plan for FY 2021 to 2025. The plan articulates the NIH's highest priorities, explains how they will achieve them, and provides updates on the outcomes of the previous plan's implementation, including accomplishments, new initiatives, and improvements. This plan is used to help enhance research coordination, better analyze research portfolios, and improve reporting methods for data as they become available and will be updated every 5 years.

Dr. Anderson reported on the strategic plan framework and its objectives, including support for research areas, research workforce and infrastructure, stewardship, and conduct. To explain the first objective, to advance biomedical and behavioral science, he highlighted a few specific research program examples including: AI for datasets research, the BRAIN Initiative, and the HEAL Initiative. The second theme is to develop, maintain, and renew the research workforce and scientific research resources and infrastructure. The third objective is to promote the highest level of scientific integrity, public accountability, and social responsibility in the conduct of science. Dr. Anderson emphasized the importance of fostering a culture of good scientific stewardship within the institution across the board, making resources like PubMed and PubMed Central available for public access to over 6-million peer-reviewed research articles.

Five themes cut across all three objectives including: minority health and health disparities, women's health, public health challenges across the lifespan, and the prioritization of collaborative and data-oriented sciences. NIH is working to align various research that supports the FAIR (Findable, Accessible, Reusable, and Interoperable) principles that would result in NIH investments for the entire research enterprise. The data is organized into five themes, including data infrastructure, strategic ways to improve data ecosystems, various tools and analytics, thorough community engagement, and workplace development.

The Scientific and Technology Research Infrastructure for Discovery, Experimentation, and Sustainability (STRIDES) aims to leverage good partnerships in the science and technology research community. Research and information that comes out of this initiative would be made available on the world's largest publicly available Sequence Read Archive, using a cloud platform. This effort remains consistent for the ACTIV research program.

The new strategic plan includes a number of bold predictions, among them: regular use of genomic information will transition from mainstream to clinical settings, new approaches to

cervical cancer screening will yield the development of self-sampling for women, infant survival will be optimized with the production of synthetic milk, researchers will develop a universal coronavirus vaccine, and the number of NIH R01 grant awards, that provide support to racially and ethnically underrepresented communities, will increase by 50% and rid disparity gaps by FY 2025.

BOR members discussed various questions and their appreciation for the three objectives of the strategic plan framework. Questions regarding opportunities for the institute be held accountable in the way plans are implemented, for various research programs, were also discussed. Lastly, BOR members noted that mid-year reviews of plan implementations would be crucial to the overall progress of projects and programs.

# VIII. MAKING NUMBERS MEANINGFUL: PROMOTING EVIDENCE-BASED COMMUNICATION OF NUMBERS IN HEALTH

Dr. Jessica S. Ancker, MPH, PhD, FACMI, Department of Biomedical Informatics, Vanderbilt University

Dr. Ancker noted the alarmingly low prevalence of health literacy and health numeracy in the United States. Despite an explosion of available health data in recent years, a significant proportion of the population is not able to benefit. Furthermore, efforts to disseminate health information have exacerbated the intervention-generated inequality stemming from low health numeracy. Dr. Ancker presented examples of research on the influence of low numeracy in health care, highlighting the distinction between mathematical and cognitive equivalence.

Dr. Ancker emphasized that health literacy and numeracy depend on a dynamic interplay between the patient, the information provider, and the information artifact; optimal alignment of these three components can increase literate or numerate behaviors. Making Numbers Meaningful, an NLM-funded project, is developing an online resource to assist health communicators in presenting numerical information. Dr. Ancker outlined the project's work in three steps: conducting a systematic literature review of the effects of data presentation on comprehension and decisions, constructing an online education and support system for communicators, and evaluating the effects of the system.

After screening nearly 27,000 studies (but analyzed only the ones that passed screening which was about 400), Dr. Ancker and her group published their initial results, regarding verbal probability terms; her group found that patients interpret verbal risk terms in highly variable ways and generally preferred the use of numbers instead. The project is also constructing an ontology of literature to help produce evidence summaries for additional literacy- and numeracy-related questions in health communication. Avoiding the use of terms with variable uses throughout the literature, outcomes will instead be classified according to a theoretically informed behavioral classification. The long-term goal of the project is to improve everyone's ability to draw meaning from health numbers through evidence synthesis, decision support for communicators, and a standard ontology for evidence.

Subsequent discussions with BOR members expanded on the influence of communicator intent on the presentation of information, as well as the responsibility of patients to self-triage to

determine the best response based on the information they receive. Dr. Ancker noted that the project will next focus on the dissemination of their online educational and support tool. Dr. Brennan also noted the need for NLM to continue to consider the themes of health literacy and numeracy in ongoing efforts to guide and educate patients.

#### IX. PRESENTATIONS OF THE REGENTS AWARD

Mr. Neil Rambo, Chair

Mr. Rambo presented the Board of Regents Award for Scholarship for Technical Achievement, that recognizes scholarly and technical achievements that enrich biomedicine, to the following individuals:

- Dr. James Rodney Brister, Staff Scientist under the Information Engineering Branch of the NCBI, in recognition of his technical excellence in developing new and effective SARS-CoV-2 analysis workflows and beta visualization products to track and understand emerging SARS-CoV-2 variants and sequence variations.
- Mr. James Mork, Acting Chief of the Applied Clinical Informatics Branch of the Lister Hill National Center for Biomedical Communications, for his technical achievements in the expansion of automated indexing, providing cost and time-savings to ongoing Medline indexing initiatives, as the lead software developer for the NLM Medical Text Indexer. His efforts will allow NLM to transition to fully automated indexing by 2022.

#### X. **CLOSED PORTION**

The closed portion of the meeting took place from 3:35 p.m. to 4:15 p.m.

#### XI. **ADJOURNMENT**

Mr. Rambo adjourned the meeting at 4:15 p.m. on September 14, 2021.

#### **Actions Taken by the Board of Regents:**

- Approval of the May 11, 2021, BOR meeting minutes.
- Approval of the September 12-13, 2023, meeting dates.

Appendix A. Roster — Board of Regents

I certify that, to the best of my knowledge, the foregoing minutes are accurate and complete.

Patricia Flatley Brennan, RN, PhD Director, National Library of Medicine

Chair, NLM Board of Regents